

FROM-

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## **EVOLUTION OF FLEXIBLE APARTMENT LIVING PROGRAM:**

Options in Community Living, Inc.

a system geared up to serving developmentally disabled persons in segregated protective environments, an apartment living program has evolved from a sheltered apartment cluster to a flexible support program for people with developmental disabilities living in their own homes. This case study will examine the evolution of one of the first apartment living programs for developmentally disabled persons in Wisconsin and the elements of it which are important for the future of residential services in Wisconsin.

Options in Community Living, formerly known as RFDF Apartments, was established in 1974 by the same parent-run RFDF Board which set up Orchard Hill. Many parents on the RFDF Board believed that developmentally disabled persons would need continuous access to staff living nearby in order to function in the community. The job descriptions of the staff closely resembled the houseparent role in a group home. It is probably not coincidental that RFDF developed its "transitional" group home after RFDF Apartments removed its live-in staff.

The staff hired for the apartment living program have had a strong value commitment to handicapped people having control over their lives. Without exaggerated preconceptions about the limited capacity of developmentally disabled people, the staff were sensitive to their clients' desires for autonomy and consciously sought to treat them as adults.

The original clients in the RFDF Apartment program came mostly from institutional settings like the State Centers, Lakeshore Manor nursing home, and Mendota Mental Health Center many of these clients had been frustrated by their experience with staff in the institutional settings who would often impose rules that made it impossible to control their own lives. Some people entered the apartment living program because they could not adjust to the structure of more restrictive residential programs. Other clients who came from their parents' homes had the natural desires of young adults to leave home and become more independent. Although the RFDF Board continued to want a more sheltered environment, the RFDF Board's preoccupation with the survival of Orchard Hill, where many of the family members of the Board resided, enabled the RFDF Apartments staff to modify the apartment living program in accordance with their experiences.

The apartment living program originally consisted of five apartments leased in a multi-unit apartment building. To facilitate social integration and access to community resources, the apartment building was located on a bus line in a residential neighborhood. Four of the apartments were sublet to groups of four developmentally disabled persons while the fifth apartment was used for live-in staff. By 1976 the live-in staff were removed and the fifth apartment was converted into an office which is staffed in the afternoons and evenings corresponding to the residents' schedules.

As the program progressed many of the original residents in the clustered site increased their independent living skills and wanted to avoid the hassles of sharing a two-bedroom apartment with four adults. Living in an apartment building with college students and doctors reinforced the goals of many in the apartment living program to set up their own apartments. This created a need to develop follow-along services for a growing number of "graduates" from the clustered site who still needed support services while living in their own apartments. 7

The cost of the apartment living program contract with the Dane County 51 Board is approximately \$130 per person per month today which is considerably below the cost of the typical group home or ICF/MR. The clients in the apartment living program pay for their own rent, food, and living expenses out of their SSI checks or wages from competitive employment.

WITH GROWING DEMAND for the apartment living program, a second cluster of five apartments was rented by RFDF Apartments in 1976 in a housing complex of garden apartments on the opposite side of town. By 1977, the live-in staff were removed from the second cluster of apartments, and the outreach program continued to expand to "graduates" of the apartment living program who moved into more independent settings.

With greater awareness of the importance of normalization and a realization that outreach in scattered sites could prevent people from returning to more costly and more restrictive settings, the 51 Board was willing, for the first time in 1979, to include outreach services to "graduates" within the contract for the apartment living program. A capacity building grant from the Bureau of Developmental Disabilities in 1980 permitted RFDF Apartments to expand its outreach services to developmentally disabled people in the community who had not participated in the sheltered apartment program. At this point there were more people receiving outreach services in scattered sites around town than in the clustered sites leased by the apartment living program. When the time came to renew its contract for 1981, the RFDF Board abruptly severed its ties with the existing apartment living program and submitted a new proposal to the 51 Board which closely resembled its original conception of an apartment living program in 1974. But the RFDF Apartment staff formed a new corporation, Options in Community Living, with a new Board of Directors for a continuation of the program with the same clients. Recognizing the importance of the continuity of relationships between the staff and the existing clients as well as the value of the outreach program, the 51 Board contracted with Options for the cost of staff support at the clustered sites and outreach to both "graduates" and non-graduates alike in more independent settings.

THE APARTMENT LIVING PROGRAM concentrates on three "main functions: (1) training in independent living skills like shopping, cooking, cleaning, money management, and home maintenance; (2) building self-confidence and assertiveness skills in relating to roommates, landlords, salesmen, etc.; and (3) hooking people up with community resources which can address their varied needs.

People learn independent living skills by living in an apartment with two or three roommates on the average. Staff work intensively with clients to help them develop techniques to function independently. One mentally retarded person who has difficulty adding and subtracting has learned to balance his checkbook with the aid of a calculator. Another person with a brain injury is learning how to use recording devices to compensate for memory loss. Many of the participants in the apartment living program have learned to use public transportation to get around town for work, chores, and leisure activities.

The staff also provide counseling in the areas of relationships, communication, self-concept, and problem-solving. Clients learn how to talk out their frustrations and to act assertively. Instead of trying to enforce organizational rules about how to run an apartment, the apartment living staff facilitate communication between roommates to remind people how to take care of themselves and be sensitive to each

other's needs. This is easier to learn in an apartment with one or two well-matched roommates than among eight or more residents in a group home or nursing home who were selected to fill a vacant slot.

As the system moves to disperse services which were once concentrated in institutions, service coordination in a fragmented community system has increasingly become a major bottleneck to living in the community. With limited resources at its own disposal, Options in Community Living tries to help clients obtain access to a wide range of community resources including housing, transportation, vocational programs, leisure activities, and financial assistance. It is not uncommon for an Options client to receive housing assistance and attendant services from the local Center for Independent Living, occupational therapy from the certified public health agency, recreation from a voluntary non-profit service provider, and a supportive relationship from a friend and citizen advocate through a local citizen advocacy program. To assure appropriateness and continuity of services, the staff of Options in Community Living perform the essential functions of service coordination and follow-along to assure that services change as the individual's needs change.

— The philosophy of the apartment living program has clearly evolved from imposing certain program requirements on participants to finding more individualized ways to help people function in the community. This shift was brought to the fore when the staff spent over one and one-half years trying to make a client "fit" the program's expectations of participating in a formal day program. The staff knew that this person had been terminated from two previous residential facilities for angry outbursts and aggressive behavior because he had been either unable or unwilling to comply with the expectations of these programs. Instead of rejecting this person from the program for not conforming to the program requirements, the staff realized that he was indeed surviving in the community in his own unstructured way, and they decided to contract with him to work on some goals that he chose himself. As it turned out, what was more important to this individual than working or volunteering was learning to read and so he has been involved in a literacy training program for almost a year where he is learning a functional skill while increasing his confidence and self-esteem. This experience has helped staff to appreciate that they do not want to make decisions for people but to help them become responsible for the consequences of their own actions.

In another revealing incident a person chose to purchase \$1500 worth of woodworking equipment at a shopping mall. Through a double-signature checking account, the staff are in a position to monitor these budgeting decisions. But rather than interfere with this choice, the staff sought to help the client make up his own mind by emphasizing the consequences of his actions. (He purchased the equipment.) Deciding to work to pay for something that one wants to purchase can be much more motivating than participating in a sheltered workshop because it is a requirement of the program. About one-half of Options' clients are involved at least part-time in competitive employment.

PARTICIPANTS IN OPTIONS IN COMMUNITY LIVING have a wide variety of needs. Some require frequent personal contacts with staff five or six times a day during a crisis period. Others are able to function with telephone contacts once or twice a month. Many of Options' clients have disabilities similar to developmentally disabled residents in group homes and nursing homes. The type of need often does not correspond to the severity of a person's disability. Some individuals labeled "mildly retarded" may require substantial support. The ability

**Figure 4: Dispersion of scattered-site apartments throughout Madison for 75 developmentally disabled persons receiving services from Options in Community Living.**



- denotes apartment
- ▶ staff office

people with disabilities to function in the community largely depends on the availability of appropriate supports. One man with a brain injury and a prosthesis on one leg gets around slowly on crutches and occasionally uses a wheelchair. Options staff helped him find a physically accessible apartment with a rent subsidy and a roommate, helped him develop independent living skills in cooking, meal planning, shopping, and self-management of his extensive health needs, and assisted him in securing home maker and chore services from the county Department of Social Services, job training from Division of Vocational Rehabilitation and Vocational Education Alternatives, mobility training from a special university program, and arranged for the purchase of a three-wheel bicycle through Medicaid. In addition, Options staff provided counseling for depression and helped him join a local church group. After one year this man no longer needs chore services, uses city buses to get around town, cooks and shops independently with his roommate, and handles his own finances. At the beginning daily visits were required from staff in addition to several phone calls a day. After a year the staff see him about once a week and have phone contact once a day.

With Options' emphasis on scattered site apartments, program participants with physical disabilities can now be served in physically accessible units who had been excluded by architectural barriers from the clustered site apartments. In scattered sites Options staff can also serve married couples and disabled persons with children. There have been nine marriages among program participants over the past six years which sometimes calls for Options staff to add counseling on getting along with the in-laws" to the other survival skills in the community. It is gratifying to staff, who have all been involved in the program from two to six years, to see people, who once lived in the clustered sites and required personal

contacts several times a day, now drive across town from their independent apartments with their spouses for visits once a month. Five couples have continued to receive outreach services since their marriages.

A scattered site apartment may not be ideal for everyone. Some individuals may prefer a clustered site to maintain peer interaction with other people with developmental disabilities with whom they may share certain interests and needs in common. Whether a person wants to live in a scattered site or a clustered site depends on individual preference and an apartment living program should be able to respect and accommodate that individual choice.

A few persons in the apartment living program may be able to function without any assistance from the outreach program after a while. Most will be able to function with minimal assistance except in times of crisis. Others will probably always need a great deal of assistance in living in the community. But even for these people, the cost of helping them fulfill their potential in an apartment setting with off-site supports will almost invariably be less costly than the cost of service to them in a nursing home, group home, or institution.

In a truly individualized program, people will have different personal goals. Even in the more structured clustered site apartments, one is struck by the diversity of dreams that roommates have as they chart their own paths to personalized fulfillment. One person wants to earn money to buy a car and move to his own apartment. Another is planning to enter Madison Area Technical College to specialize in a career in food preparation. A third is concerned about spirituality and playing drums. Options in Community Living is an individualized program not only because of the staff-to-client ratio or the small number of persons in each apartment, but also because the staff and clients both have the expectation that the clients are responsible for their own actions. The expectation is not that all people must be able to do the same things in order to live in an apartment but that the program must have the capacity to accommodate people's changing needs.

The RISING COST of group homes and the growing realization that many severely disabled persons can function well in an apartment have increased the Dane County 51 Board's interest in the apartment living program. A recent site visit by the 51 Board members brought the reality of people's lives to the attention of the 51 Board. Having shaken their hands, drunk their coffee, eaten their dessert, and asked about their future plans, the 51 Board members appeared more convinced that the apartment living program is a viable alternative to more restrictive and more costly residential facilities.

With the reorganization of the apartment living program since its break with the RFDF Board, Options in Community Living has established a new broad-based board of directors bringing together experts in the areas of business, law, real estate, government, local politics, education, social services, and health, to join representatives of family members, advocates, consumers, and staff. This new board will plan the next stage of Options' evolution and growth as an innovative apartment living program. If Options intends to serve people in the community with more severe disabilities, it may have to consider restoring the use of live-in staff where needed and to develop an effective use of para professionals.

The evolution of this apartment living program has occurred through the personal growth of clients and staff over the past six years. It remains to be seen whether their experiences will help other residential programs develop a flexible capacity to individualize services that enable more developmentally disabled persons to live in the community. 1

# Options in Community Living

Administrative Office: 1954 East Washington Ave., Madison, Wisconsin 53704, Phone (608) 249-1585 |

## MISSION STATEMENT

Options in Community Living, Inc. (Options) believes that every person has the right to live in a home in the community as an active and accepted member. Its mission is to provide support and coordinate services to enable adults with developmental disabilities to live on their own in small, dispersed settings. The agency works with people to help them make their own choices and reach their own goals, with support available as often and for as long as it is needed.

Guided by an active board representing a diverse group of persons, Options strives to help people with disabilities and the larger community learn from each other in order to promote mutual understanding, personal satisfaction, and a greater fulfillment of the potential of each individual.

OPTIONS IN COMMUNITY LIVING, INC.

DEMOGRAPHIC INFORMATION

NUMBER OF OPTIONS CLIENTS SERVED TO DATE IN 1983 . . . . .95

<u>SEX</u>		<u>AGE</u>	
Male . . . . .	37	Under 20 . . . . .	0
Female . . . . .	47	20 - 25 . . . . .	31
		26 - 30 . . . . .	16
		31 - 35 . . . . .	16
<u>MARITAL STATUS</u>		36 - 40 . . . . .	12
Single . . . . .	88	over 40 . . . . .	19
Married . . . . .	7		

<u>DAY ACTIVITY</u>		<u>RESIDENCE AT TIME OF CERTIFICATION</u>	
Paid Employment . . . . .	37	Intermediate Care Facility .	21
Volunteer Employment . . . .	19	Group Home/Halfway House . .	17
Sheltered Workshop . . . . .	22	Adult Foster Care . . . . .	6
Student . . . . .	7	Family Home . . . . .	35
Homemaker . . . . .	2	Independent Living . . . . .	8
Unemployed . . . . .	10	Nursing Home . . . . .	4
None . . . . .	5	YMCA/YWCA . . . . .	2
		Hospital Rehabilitation Unit	2

<u>DIAGNOSIS</u>	<u>Primary</u>	<u>Secondary</u>
M.R. . . . .	59 . . . . .	18
C.P. . . . .	17 . . . . .	1
Epilepsy . . . . .	10 . . . . .	6
Brain Injury . . . . .	7 . . . . .	0
Mental Illness . . . . .	2 . . . . .	10
Hearing Impaired . . . . .	0 . . . . .	2
Vision Impaired . . . . .	0 . . . . .	2
Other . . . . .	1 . . . . .	1

<u>INCOME SOURCE</u>		<u>ANNUAL INCOME</u>	
SSI . . . . .	10	Unknown or 0 . . . . .	5
SSDI . . . . .	1	\$3000 - 3999 . . . . .	5
SSI/Child Benefits . . . . .	1	4000 - 4999 . . . . .	38
SSI/Employment . . . . .	7	5000 - 5999 . . . . .	24
SSI/SSDI . . . . .	22	6000 - 6999 . . . . .	11
SSI/SSDI/Employment . . . .	21	7000 - 7999 . . . . .	3
SSDI/Employment . . . . .	2	8000 - 8999 . . . . .	2
Employment . . . . .	22	9000 - 9999 . . . . .	3
Welfare . . . . .	1	10,000 - 10,999 . . . . .	0
Welfare/Employment . . . . .	2	11,000 - 11,999 . . . . .	1
A.F.D.C. . . . .	1	12,000 - 12,999 . . . . .	1
Other . . . . .	3	13,000 - 13,999 . . . . .	1
None/Unknown . . . . .	2	14,000 - 14,999 . . . . .	1

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# Options in Community Living

Administrative Office: 1954 East Washington Ave., Madison, Wisconsin 53704, Phone (608) 249-1585

## VOCATIONAL STANDARDS POLICY

The purpose of this paper is to outline some vocational standards which Options in Community Living believes will improve the overall quality of life of our clients. Options maintains that the expectations for the vocational quality of life for persons with disabilities should be the same as those for other community members.

The standards in this paper address vocational service components such as wages, job stability, amount of work, and follow-along support. These are the areas which, as documented in the Vocational/Activity Profile, impact upon a large number of Options clients.

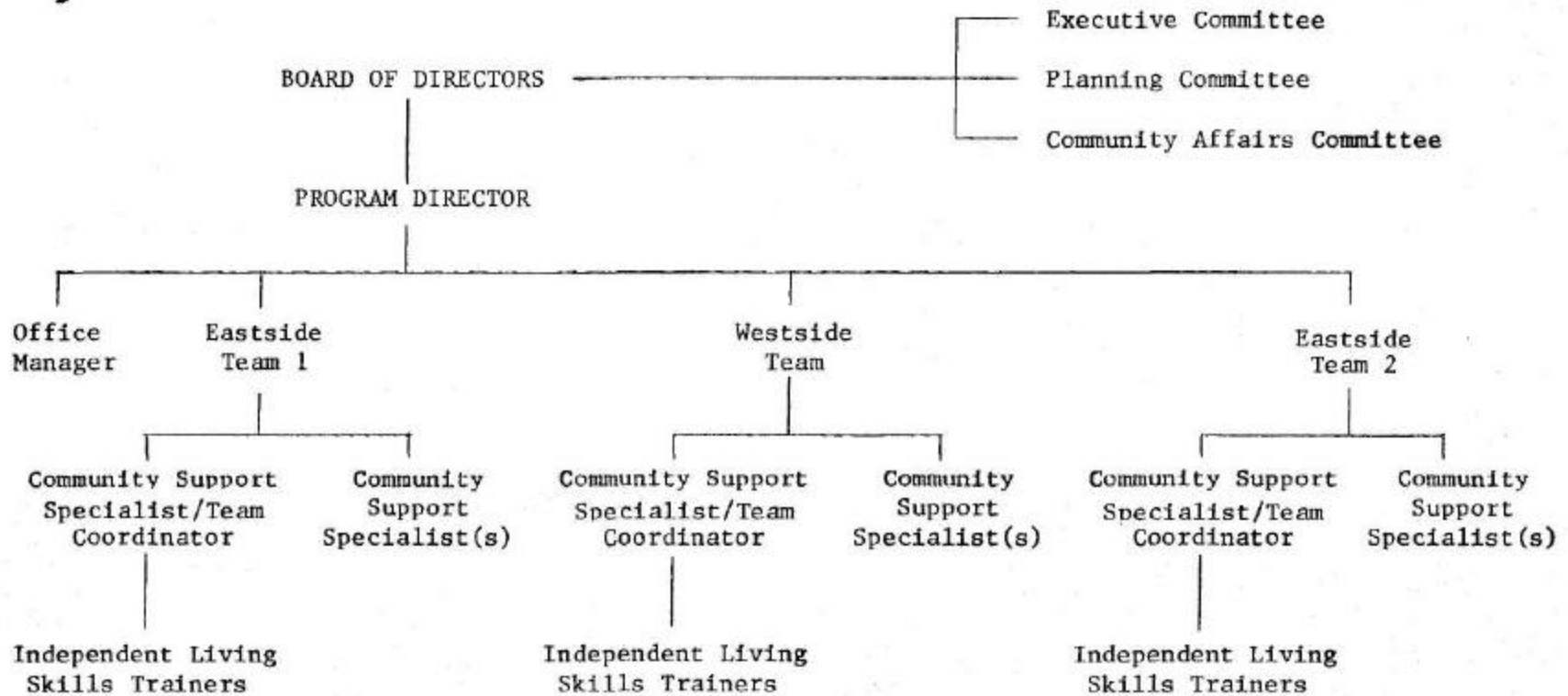
We feel that these standards are a necessary component of all vocational services. These standards will assist Options with the planning and evaluation of our clients' vocational needs.

- 1) A person should have a range of choices regarding the type of work he/she would like to pursue and a right to explore and pursue his/her career goals.
- 2) A person should have the opportunity and right to choose the number of hours he/she would like to work.
- 3) For a person who earns either no wage or less than minimum wage, there should be a system to regularly review and justify why that person does not earn minimum wage.
- 4) A person should have the appropriate type and amount of follow-along support necessary to sustain him/her in employment. The support should be available from community based providers as well as sheltered workshops.
- 5) There should be a limit set on the length of time a vocational provider has to find a job for an individual.
- 6) SSI reduction for paid employment:
  - A person should be able to earn the maximum amount of income in conjunction with maintaining SSI benefits.

- In making a decision between employment and SSI benefits, efforts should be made to balance all factors that would affect a person's quality of life.
- If a person incurs the risk of losing SSI benefits, adequate protections should be established with regard to earning appropriate income and maintaining necessary medical benefits.

OPTIONS IN COMMUNITY LIVING, INC.

ORGANIZATIONAL CHART





# Options in Community Living

Administrative Office: 1954 East Washington Ave., Madison, Wisconsin 53704, Phone (608) 249-1585 |

## PROGRESS REPORT

### CAPACITY BUILDING GRANT FOR PEOPLE WITH SPECIAL NEEDS

March, 1983

In response to a growing demand for services for persons with multiple developmental and physical disabilities, the Dane County Unified Services Board, in cooperation with several community agencies, applied for and received a Capacity Building Grant from the Wisconsin Department of Health and Social Services in July, 1982. Options in Community Living, Inc., was the agency designated to implement this grant with a mission of demonstrating viable community residential alternatives for six adults whose needs required intensive and long-term supports.

The grant proposal process required that the project planners identify the specific people to whom services would be offered. This provided a rare opportunity for services to truly be designed around the individual's needs and preferences, versus trying to "fit" people into frequently ill-fitting programs. Now, eight months later, we have learned some interesting things about providing services to people with multiple and severe disabilities, which are outlined in this report. We have also completed assessments and service planning with eight individuals, which has led to the following results:

In September, 1982, a 19-year-old man who attends a Madison high school moved into a rent-subsidized two-bedroom apartment with a live-in attendant. He has cerebral palsy and mild mental retardation, cannot walk or transfer independently, and has severely impaired speech. Although his apartment was not built as an accessible unit, a ramp and adaptive equipment have made this a satisfactory home. This man receives a great deal of support from family members who live nearby, as well as services from Options.

In October, a 21-year-old woman and recent high school graduate moved from her parents' home in rural Dane to a new, accessible, rent-subsidized unit on Madison's east side with a live-in attendant. She has cerebral palsy, is mentally retarded and cannot walk or transfer independently. She has supportive relationships with her family and with friends in Madison, maintains a volunteer job three days per week, and receives services from Options.

In October, Options also began working with two women, ages 25 and 34, who were sharing a three-bedroom, accessible apartment with one live-in attendant. They were referred to this project because they were not receiving an adequate level of support services and because they found their shared living arrangement unsuitable. Negotiations with the owner of the complex have resulted in plans for the women to move to separate two-bedroom units with their own attendants. One woman presently attends classes at MATC and both are on waiting lists for volunteer jobs. Both women have cerebral palsy.

In January, 1983, a 60-year-old man moved from the Dane County Home to a rent-subsidized, two-bedroom apartment. In addition to having cerebral palsy and speech and hearing impairments, he suffered a back injury two years ago and is unable to walk or transfer alone. Because he requires 24-hour attendant care, a couple was recruited to live with him and a relief worker is scheduled several times each week. He has never enjoyed group activities or programs, so one-to-one activities are planned with his attendants, Options staff and University students.

The sixth individual identified for the project was a 54-year-old woman who has cerebral palsy and who has resided at the Dane County Home for 21 years. Although she has periodically verbalized a desire to move into the community, she is now highly ambivalent about such a move and has no immediate plans to do so.

In February, Options added two additional men to the project who, although not physically disabled, required a greater level of services than was presently available in an apartment setting. These men, ages 20 and 23, have moved into a three-bedroom flat with another young man who has been licensed as a foster sponsor and who provides minimal supervision and overnight support as a supplement to Options services. One man is about to complete high school and the other has a part-time job. Both men are mentally retarded and one man has a severe seizure disorder.

#### SOME SUCCESSFUL STRATEGIES

The project staff consists of a Coordinator (80% FTE) who is responsible for program development, social services and case management, and an Independent Living Skills Trainer (full-time) who assists people in a wide range of daily living activities. Due to the scarcity of successful service models for this group, Options staff sought input from a variety of knowledgeable persons in developing these services. An advisory group consisting of Don Anderson (Waisman Center), Sally Mather (WARC), and Dan Remick (consumer representative), met several times in 1982 to discuss such issues as attendant care, resources for daytime activities, and potential research topics. Options also contracted with the following people for assistance in individual assessment and service planning: Marianne Jacobs of United Cerebral Palsy; Access to Independence; Mark Sweet, Doctoral Student in Behavioral Disabilities, UW-Madison. These varied perspectives have been extremely useful in developing new services.

Another useful strategy has been an assessment process that is based largely on an approach outlined by the Developing Individualized Services Options (DISO) Project (Marcie Brost, Director).<sup>1</sup> Our assessments involved gathering information from clients, their families and professionals with our goal being to "get to know" the person e.g. important people and activities in their lives, their individual preferences and future goals, the help they would need in order to live in the community. We found that informants frequently held conflicting opinions about the client and, consequently, it was helpful to contact at least several people who knew the client well and to observe him/her in different settings.

We have also found that it is critical for someone to assume a case management role with persons who cannot assume total responsibility for their own personal planning. This has included both the setting up and monitoring of services by someone who has a familiar and on-going relationship with the client. In some cases, staff time spent on case management has surpassed the time spent providing face-to-face services. This was particularly true for the 60-year-old man who moved into an apartment from a nursing home. Because he has only a minimal natural support system and has speech and hearing impairments which make it difficult for him to communicate, Options staff has assumed major responsibility for arranging the services he needs and wants, including attendant care, medical and dental services, Social Security benefits, medical insurance, home care allowance, COP funding, speech and hearing services, and banking services. We anticipate that, for most clients, this case management role will be needed on a long-term basis.

A necessary component of each person's service plan has been to obtain the financial resources necessary for a live-in attendant or support person. This has been minimally accomplished through the use of funds from the Supportive Home Care and Foster Care programs, and with rent subsidies which allow the live-in person to receive free rent. In addition, Options supplements the salaries of personal care attendants for their assistance in teaching daily living skills. COP funding has also been obtained for one person who required 24-hour attendant care.

In the area of direct services, Options has had to re-evaluate and adapt its approach to skill development with its goal of "independence". As we've gained more experience with persons who have severe and multiple disabilities, we are rethinking the meaning of "independence" and "autonomy". Ann Falconer, a physical therapist at Madison East High School, described to us her emphasis on teaching severely handicapped persons to be "independent, though dependent", i.e. learning to effectively direct others to do "tasks that are not possible or practical for the individual to do alone."<sup>2</sup> Baumgart, Brown, Pumpian et al. (1982) introduced us to the "principle of partial -participation" which "is essentially an affirmation that all severely handicapped (persons) can acquire many skills that will allow them to function, at least in part, in a wide variety of least restrictive... activities and environments."<sup>3</sup> This principle encourages the development of chronological age-appropriate and functional skills, and recognizes the need to prioritize the activities that are most valuable for each individual to learn.

BARRIERS TO SERVICES

Although it has been the sincere intent of this project to develop services around the specific needs of each individual, we have encountered various barriers which restrict people's choices. Many of these barriers are related to the limited resources of publicly funded programs and the limited personal finances of severely disabled persons.

One significant problem has been that the attendant/employer residential model has not been the optimal arrangement for some of the clients served by this project. It has been unrealistic for us to expect certain persons to assume the employer role and the responsibilities of directing their own personal care, despite a great deal of support from Options and other agencies. This has been true for our two youngest clients and for the woman who has lived most of her adult life at the Dane County Home. A preferable arrangement might have been a small group living situation with persons of similar age and interests with paid staff who lived in or worked in shifts. This would have allowed a more gradual introduction to the demands of independent living and attendant supervision. Unfortunately this project has been unable to provide or generate the funds for such a setting.

A related problem is the universally low wages paid to direct care personnel who work with disabled adults in community settings. The home care allowance, which is intended to cover both live-in and relief attendant wages, ranges from \$375.00 to \$500.00 per month for the clients served by this project, and does not include health insurance, paid vacation or other such benefits. Even when free rent and a \$100.00 monthly supplement from our agency is added, the compensation for the demands of these positions remains disturbingly low. A direct consequence has been difficulty in recruiting and keeping qualified attendants. The two women who share an apartment have had three attendants in two years. A third woman has had three attendants in five months. This frequent turnover of live-in attendants, on whom our clients so heavily depend, has extremely disruptive effects on their lives.

Another barrier to community living has been a shortage of.... services that are necessary for severely disabled persons to fully participate in community life. Although such services do exist in the Madison area, they frequently lack the capacity to meet the large demand. One important example is the Elderly/Handicapped Bus Service which due to its limited resources, has become increasingly difficult to schedule for work and other important community activities. Another example is limited availability of paid or unpaid work opportunities for severely disabled persons in integrated community settings. Although Vocational Education Alternatives has been successful in developing some such positions, clients have frequently waited for many months for their services. This, in turn, has obvious adverse effects on attendant care schedules.

A barrier that is not related to funding is that of attitudes. During the course of service planning with some individuals, we encountered resistance and skepticism, from families and professionals, to the idea that a severely disabled person can live in a small, integrated community setting if given adequate support services. Some people raised justifiable concerns which aided the planning process, while others were not interested in even considering the possibility. The most notable example of such disinterest was one physician who concluded that our client was not "a candidate for independent living" without considering information on available support services in the community which we had offered to provide.

#### CONCLUSIONS

As we move ahead with this project, we hope to develop creative approaches to overcoming the barriers to providing services to severely disabled persons in normalized, community settings. We are encouraged by the interest in and commitment to this group that has been demonstrated by the Unified Services Board, the Madison Public Schools, community agencies and family members. With their continued support, the staff hopes to develop some workable solutions to problems related to attendant care resources, choice of residential settings, and availability of community services for severely disabled adults.

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Project Coordinator  
March 3, 1983

OPTIONS POLICY ON QUALITY OF LIFE

By: Options in Community Living, Inc.

June 1, 1983

Options in Community Living, Inc.  
1954 East Washington Avenue  
Madison, Wisconsin 53704

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## OPTIONS POLICY ON QUALITY OF LIFE

### Introduction

The mission of Options in Community Living is to provide support and coordinate services to enable adults with developmental disabilities to live on their own in small, integrated community settings. The agency works with people to help them make their own choices and reach their own goals, with support available as often and for as long as it is needed.

Because our clients rent their own apartments which are not subject to licensing, any government regulations, or agency control, Options felt a responsibility to develop quality-of-life standards that apply to people who live in apartments or other similar community residences. We maintain that the expectations for quality of life for persons with disabilities should be the same as those for other members of the community. Support must then be provided on an individualized basis to help our clients achieve these standards

The purpose of this document is three-fold. First it serves to provide staff with standards for evaluating an Options client's well-being and identifying areas where intervention is needed. Secondly, it provides the agency with guidelines for determining which individuals or groups are best served by this service model. These standards are not intended to be used as entrance criteria, but rather as a general framework for assessing community living needs.

The third purpose is to communicate to our consumers, their families, advocates, and professionals the principles that guide our services. We encourage open dialogue with our consumers and other interested parties about these principles and how they are implemented.

The policy addresses eight major aspects of community living. Each area is divided into two sections: 1) a list of those conditions that we feel must exist to ensure that people are not at risk in the community, and 2) a list of further conditions that Options will actively promote to help its clients achieve a valued lifestyle. It is anticipated that some people will need intensive and long-term support to maintain these standards.

A final comment must be made about the implementation of this policy. We believe that the responsibility for quality of life is shared by service providers, the consumer, and his/her significant others. Options' services are voluntary and we will actively promote, but cannot enforce, these standards. We respect the right of our consumers, with support from their families and advocates, to assume responsibility for their life decisions.

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I. Personal Income

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person has a stable source of income that covers his/her basic living needs, including shelter, food, transportation, clothing.
  - 2. There is effective management of this income to ensure that basic needs are met. (Support can be provided when needed through a double-signature bank account, representative payee, or assistance with budgeting.)
- B. Conditions that will further promote a valued lifestyle:
  - 1. There is sufficient income for items and activities that enrich one's life experience, such as vacations and other leisure activities, home decorations, and items that enhance one's personal appearance.
  - 2. The person is able to participate as fully as possible in decision-making about the use of his/her personal income through the development of money and budgeting concepts and values that encourage financial responsibility.
  - 3. The person can maximize his/her income through wise investments and purchases, and through subsidies for which he/she is eligible.
  - 4. The person has a means of earning income through employment as a supplement to or in place of government benefits.



## II. Housing

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person has housing that meets community building codes, is secure and has adequate heat, water and electricity.
  - 2. The person has the basic furnishings necessary for daily living, including a bed, chairs, table and lighting.
  - 3. The person lives in a neighborhood where he/she feels safe and where there is access to needed resources.
- B. Conditions that will further promote a valued lifestyle:
  - 1. The interior and exterior of the home is maintained in a safe, clean and attractive fashion.
  - 2. The person is able to exercise control over his/her home environment, including choice of location, personalized furnishings and decor, and control of temperature and lighting.
  - 3. The home furnishings are attractive and complete.
  - 4. The person is able to have maximum influence over his/her housing situation through such means as participation in a tenant association, cooperative housing or home ownership.

### III. Physical and Mental Health

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person's health is maintained through adequate nutrition, exercise, safe behavior, medical monitoring, and appropriate medications when needed.
  - 2. The person receives prompt and up-to-date treatment for physical and mental health problems.
  - 3. The person employs a personal care attendant if his/her physical disability limits his/her ability to provide self-care.
- B. Conditions that further promote a valued lifestyle:
  - 1. The person has established relationships with and easy access to health care providers (e.g. physicians, nurses, dentists, counselors and therapists) that know the person and monitor his/her health needs on an on-going basis.
  - 2. The person's lifestyle encourages "wellness". For example, he/she eats nutritious meals on a regular schedule and maintains an appropriate weight; he/she does not smoke; he/she does not drink in excess or use drugs; he/she has coping mechanisms to relieve stress; he/she has people to provide emotional support.

#### IV. Safety

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. Potential dangers in the person's environment are minimized. For example, his/her home is free of fire hazards; his/her home is locked and secure; he/she does not walk alone on dark streets at night.
  - 2. The person receives prompt and appropriate emergency services when needed, such as police, fire department, ambulance, crisis line.

#### V. Appearance and Hygiene

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person minimizes health related problems through adequate personal hygiene and clothing choices that are appropriate for weather conditions.
  - 2. The person maintains acceptable hygiene and appearance so as not to restrict where he/she can live, work and socialize.
- B. Conditions that will further promote a valued lifestyle:
  - 1. The person has a choice of attractive clothing for different occasions.
  - 2. The person maintains his/her hair in a manner that is becoming.
  - 3. The person's hygiene and appearance serve to enhance self-esteem.

VI. Relating with Others

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person has the means to communicate on a daily basis with primary people in his/her life. (This may include speech, signing and adaptive devices.)
  - 2. The person has support people, including Options staff, with whom they are able and willing to maintain contact.
- B. Conditions that will further promote a valued lifestyle:
  - 1. The person has the means of communicating in such a way that encourages interactions with other members of his/her support system and community (e.g. clarity, assertiveness, appropriate affect).
  - 2. The person has supportive relationships with family members that encourage independence.
  - 3. The person has relationships with friends and peers which provide companionship, intimacy and support.
  - 4. The person has the opportunity to responsibly engage in sexual relationships and marriage based on his/her personal beliefs and values.
  - 5. The person's relationships include people who are non-disabled.

## VII. Meaningful Activities

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person has a daily routine that is designed around his/her needs and capabilities and that resembles as closely as possible a typical adult routine. Such a routine is likely to include vocational, domestic and leisure activities.
- B. Conditions that will further promote a valued lifestyle:
  - 1. The person's activities provide opportunities for personal growth and increased life satisfaction.
  - 2. The person receives wages for his/her work.
  - 3. The person takes part in culturally-valued leisure activities, such as parties, trips, concerts and shows.
  - 4. The person's activities take place in community settings that are integrated with non-disabled people.
  - 5. The person has the means of developing and achieving short-term and long-term goals (e.g. vocational planning, vacations, retirement).

## VIII. Mobility

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  - 1. The person has the means to move about his/her home and community environments to the extent necessary to satisfy his/her basic needs.
- B. Conditions that will further promote a valued lifestyle:
  - 1. The person has physical access to a wide range of community resources for work, leisure, shopping, etc. Modes of transportation can include bus, car, bike, walking, vehicles equipped for wheelchairs.
  - 2. The person, when needed, has adaptive devices that will enhance his/her mobility, such as canes, motorized wheelchair, three-wheel bike.